Health-Related Quality of Life and Related Factors in Children and Adolescents With Epilepsy in Iran

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ABSTRACT

The effects of epilepsy may disturb the ability of the child and family to function and has detrimental effects on health-related quality of life (HRQOL). We determined HRQOL and related factors in children and adolescents with epilepsy in Iran. This cross-sectional study was performed in a private neurology pediatric clinic in Guilan Province (North of Iran). We evaluated 108 children and adolescents with epilepsy. Data were collected by interview with parents and review of medical records. Generic and specific HRQOL was evaluated by Child Health Questionnaire and QOL in Childhood Epilepsy Questionnaire, respectively. The mean of overall generic HRQOL score was 71.05 ± 11.31. The lowest score was related to parental impact: emotional (52.59 ± 15.49). The average total specific HRQOL score was 71.95 ± 11.16. The lowest score dedicated to general health (51.21 ± 18.25). In multivariate regression analysis, duration of epilepsy ($p < .016$) was independently associated with generic HRQOL scores. Variables were independently associated with specific HRQOL scores including gender ($p < .003$), duration of epilepsy ($p < .011$), and family history of epilepsy ($p < .005$). We found that epilepsy duration was the strongest predictor of both generic and specific HRQOL in children and adolescents with epilepsy. This will be useful for clinicians in epilepsy management, which will enhance HRQOL.

Keywords: adolescent, children, epilepsy, quality of life, seizure

Epilepsy is one of the most common neurologic disorders in childhood (de Souza Maia Filho, Streiner, & da Mota Gomes, 2007; Taylor, Jacoby, Baker, & Marson, 2011) recognized by repetitive seizure activity (Modi, Ingerski, Rausch, & Glauser, 2011), affecting 3.6–4.2 per 1000 children in developed countries and almost a doubled number of these rates in developing countries (Mathiak et al., 2010). In Iran, the prevalence rate is about 1.8% (Hosseini, Sharif, Ahmadi, & Zare, 2010).

Epileptic children are at more risk of psychological and psychiatric impairments (Taylor et al., 2011); they often experience daunting limitations and social stigma, fear of next seizure, medication side effects (Szaflarski, Meckler, Privitera, & Szaflarski, 2006), and poor academic achievement (Taylor et al., 2011); therefore, epilepsy impairs children's physical and cognitive health and psychosocial compatibility as evidenced by emotional, behavioral, social, and academic difficulties (de Souza Maia Filho et al., 2007). The management of epilepsy needs determination of potential impacts of epilepsy on all domains of life (Aggarwal, Datta, & Thakur, 2011). Health-related quality of life (HRQOL) is a multidimensional construct that deals with a person's perceptions about disease burden on several dimensions of life such as physical, psychosocial, cognitive, and work (Guyatt, Feeny, & Patrick, 1993). HRQOL is the main outcome that is increasingly recognized as an essential element in the assessment of the epilepsy impacts on life function and also treatment of epilepsy (Modi et al., 2009; Stevanovic, 2007). Because of considerable advances in epilepsy treatment, attention has shifted to perception of impact of the disease on mental health and HRQOL (de Souza Maia Filho et al., 2007). Epilepsy is an incongruous condition that differs based on etiology, seizure characteristics (e.g., type, frequency), clinical management, and existence of neurological pathology. However, limited research has been presented specifically on measuring the HRQOL of children with epilepsy (Miller, Palermo, & Grewe, 2003).

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Research on chronic conditions has shown that HRQOL differs based on variables such as income, educational level, occupational status, age, and gender. In comparison with this tremendous set of studies, the field of epilepsy has a scarce research on demographic predictors of HRQOL, especially on children. Understanding of effects of demographic and clinical variables on HRQOL is a main goal for determining health policy interventions (Sherman et al., 2008).

There is also much attention in comparing HRQOL between individuals with the same medical condition in diverse countries/cultures (Yam et al., 2008). On the other hand, epilepsy can be both a medical diagnosis and a social stigma, particularly in developing countries (Ronen et al., 2010; Wu, Ding, Wang, & Hong, 2010). There is an outstanding absence of studies on HRQOL among children with epilepsy from the developing countries (Aggarwal et al., 2011), with paucity of reports from Iran. In Iran, community attitudes regarding epilepsy display cultural biases, including poor acceptance of a person with epilepsy entering into the family via marriage (Ghanean, Nojomi, & Jacobsson, 2013; Masoudnia, 2009). The impact on HRQOL and its related factors in children and adolescents with epilepsy remain unknown. Realization of factors associated with HRQOL in these children is essential to plan suitable interventions (Szaflarski et al., 2006; Yong, Chengye, & Jiong, 2006). In this study, we attempt to illuminate HRQOL and related factors in children and adolescents with epilepsy in Guilan province (North of Iran).

Methods

Sample and Design

This cross-sectional single-center study was carried out between September 2010 and May 2011. Participants were 108 children attending a private neurology pediatric clinic in Rasht (Guilan province). Inclusion criteria were age between 5 and 18 years, definite clinical diagnosis of epilepsy by a pediatric neurologist (third author), and absence of major comorbidities (e.g., serious cognitive impairment, autism, or severe motor and sensorial handicaps), which may affect HRQOL.

Measures

Sociodemographic information was assessed, which included age, gender, age of both parents, occupation of parents, marital status, educational level of parents, school grade of the child, place of residence, and monthly income. The clinical characteristics included age at epilepsy onset, epilepsy duration, seizure frequency, number of antiepileptic drugs, epilepsy type, and family history of epilepsy.

These Iranian researchers examine HRQOL in children with epilepsy with a focus on issues that may be unique to developing countries.

Parents completed two self-administered HRQOL questionnaires: general HRQOL questionnaire and epilepsy-specific questionnaire.

The Child Health Questionnaire (CHQ)-28 is a generic HRQOL instrument designed for children aged 5–18 years. It is divided into eight multi-item scales and five single-item concepts. Per scale, the items are summed up (some recoded/recalibrated) and transformed into a 0 (worst possible score) to 100 (best possible score) scale, with higher scores indicating better function. Physical summary items included physical function (three items), role limitations: physical (one item), general health perceptions (four items), and bodily pain (one item). The psychosocial summary considered parental impact: emotional (three items), parental impact: time (two items), role limitations: emotional (one item), self-esteem (three items), general behavior (four items), mental health (three items), family activities (two items), family cohesion (one item), and change in health (one item). "Parental impact: emotional" is defined as emotional concerns as to a child's physical and emotional health, whereas "role limitations: emotional" is defined as limitation of the child's school or peer activities because of emotional or behavioral concerns. The CHQ summary scores for physical and psychosocial function were compared with normative data (standardized mean = 50, SD = 10; Landgraf, Abetz, & Ware, 1996). The reliability and validity of the questionnaire had been established (Raat, Botterweck, Landgraf, Hoogeveen, & Essink-Bot, 2005).

The QOL in Childhood Epilepsy Questionnaire (QOLCE) is a 76-item parent-rated and epilepsy-specific instrument to measure the HRQOL of children aged 4–18 years. QOLCE consists of 16 QOL subscales covering five domains of life function: (a) physical function (physical restrictions and energy/fatigue), (b) social function (stigma, social interaction, and social activities), (c) emotional well-being (depression, anxiety, control/helplessness, and self-esteem), (d) cognitive function (attention/concentration, memory, language, and other cognitive), and (e) behavioral function. The other subscales are general health and quality of life. The scores of subscales have a possible range of 0–100, with higher scores reflecting a better function (Sabaz et al., 2000). The questionnaire has been confirmed in terms of reliability and validity (Sabaz, Cairns, et al., 2003).

The questionnaires were translated into Persian language. Following translations were conducted by an Iranian professor of English literature. Then, a native bilingual English speaker translated it back into English. Content validity was determined by gathering views of 10 medical and nursing professionals after questionnaire review. Furthermore, the questionnaires were revised. Cronbach's α coefficients were computed for all dimensions of CHQ and QOLCE to evaluate their reliability, which were .89 and .87, respectively, which indicated acceptable internal consistency.

Data Collection

All questionnaires were completed by structured and face-to-face interview when the children's parents were referred to an outpatient pediatric neurology clinic for follow-up visit. All of the data were collected by two trained nurses. One nurse interviewed the parents, whereas the other nurse interviewed the child. Sociodemographic and clinical characteristics were provided by interviewing parents and medical records review. Interviews were performed in a private room in the clinic. Each interview lasted 20–30 minutes on average. Both mothers and fathers were accepted as proxies because their evaluations had shown to be similar and interchangeable (Jozefiak, Larsson, Wichstrøm, Mattejat, & Ravens-Sieberer, 2008). A written informed consent form was obtained from parents as well as an oral consent from the children before filling the questionnaires. The ethical committee of Guilan University of Medical Sciences approved this study.

Analytic Strategy

Categorical and continuous variables were presented as mean (*SD*) and frequency (percentages), respectively. Total scores of both CHQ and QOLCE were presented as mean and *SD*. Initially, univariate correlations between children's characteristics and general and specific HRQOL were determined using independent *t* test, analysis of variance, and Pearson correlation coefficient according to normal distribution of data. Accordingly, effects of independent variables with significant correlations (variables with $p < .05$ in univariate analysis) on each dependent variable were analyzed using multiple linear regression models. For data analysis, we used SPSS version 16 (SPSS, Inc., 2007). All tests were two tailed, and statistical significance was considered for *p*s < .05.

Results

Sociodemographic and Clinical Characteristics

Subjects included 67 boys (62%) and 41 girls (38%). The mean age was 10.12 ± 3.27 years (range of 5–18 years). The sociodemographic characteristics are portrayed in Table 1, available in Supplemental Digital Content 1 at http://links.lww.com/JNN/A48.

The mean age of epilepsy onset was 5.46 ± 3.21 years (range of 1–13 years). Clinical characteristics were summarized in Table 2, available in Supplemental Digital Content 1 at http://links.lww.com/JNN/A48.

Generic and Specific HRQOL Scores

The mean total score of CHQ and QOLCE and their subscales was illustrated in Tables 3 and 4 (available in Supplemental Digital Content 1 at http://links.lww.com/JNN/A48), respectively. The mean of overall CHQ score was 71.05 ± 11.31. The highest and lowest scores were associated with bodily pain (92.12 ± 15.6) and parental impact: emotional (52.59 ± 15.49), respectively. The psychosocial summary score was very low compared with physical summary scale (69.76 ± 12.83) and normative data (50 ± 10).

The average of total QOLCE scores was 71.95 ± 11.16. The highest and lowest scores were regarding to language (83.08 ± 19.18) and general health (51.21 ± 18.25), respectively.

Univariate Analyses of Generic and Specific HRQOL

In univariate analyses, age ($p < .005$), gender ($p < .04$), child school grade ($p < .035$), and epilepsy duration ($p < .028$) were associated with CHQ scores. The duration of epilepsy ($p < .013$), gender ($p < .012$), and family history of epilepsy ($p < .04$) were associated with QOLCE scores.

Multivariable Regression Analysis of Generic and Specific HRQOL

The multivariate regression models are shown in Tables 5 and 6, available in Supplemental Digital Content 1 at http://links.lww.com/JNN/A48, for CHQ and QOLCE, respectively. Duration of epilepsy ($B = -0.67$, $p < .016$) was independently associated with CHQ scores. The children of parents who were married had significantly higher generic HRQOL. The duration of epilepsy had inverse correlation with generic HRQOL scores.

Variables were independently associated with QOLCE scores including gender ($B = 7.517$, $p < .003$), duration of epilepsy ($B = -0.72$, $p < .01$), and family history of epilepsy ($B = -0.405$, $p < .005$). There were differences in specific HRQOL scores between boys and girls. HRQOL score was lower in girls compared with boys. Specific HRQOL scores declined with increasing duration of epilepsy. Children with family history of epilepsy had lower specific HRQOL scores.

Discussion

This study reveals that generic HRQOL scores were lower for "parental impact: emotional" compared with other subscales. The impact of epilepsy occurs to all family members. It is very difficult for parents to accept that their children are diagnosed with epilepsy. They become really worried about the child's prognosis, the nature of epilepsy, the side effects of antiepileptic drugs, the probable impaired mental functions, and finally, their future. A prior study showed that parents of epileptic children are at high risk of anxiety (Li, Ji, Qin, & Zhang, 2008).

Moreover, one of the problems for parents to accept is the label of epilepsy. The stigma related to its condition causes parental distress. As the child grows older, parental stress usually increases because of management difficulties, costs, and high concerns about the child's future (Spangenberg & Lalkhen, 2006). All of these lead to high stress and burden to the family, which can explain the low score for parental emotional impact in our study.

In physical function domain, children and adolescents with epilepsy did not experience many problems. Physical summary scores were higher than normative data scores, but when compared with normative data, children and adolescents with epilepsy were rated dramatically poorer on the psychosocial summary scale. This finding was consistent with the earlier study. Connolly et al. (2006) showed that parental emotional impact accounted for 34.9% of the variance in self-esteem scores and 36% of the variance in language scores; however, the mean score for this subscale was 67.22 ± 28.53, which was higher than that of our study (52.59 ± 15.49). This indicates that epilepsy has greater influence on parents and family members in our study than in the previous study. Taylor et al. (2011) reported that parents of younger children experienced significantly more restrictions on the emotional impact, time impact, family activities, and family cohesion subscales. Similar to our study, of all subscales, the mean score of parent emotional impact was the lowest score (58.33 ± 50). In addition, results of another study confirmed that parents of children with definite epilepsy are at a higher risk of anxiety. Parental anxiety was a significant factor for children's specific HRQOL as measured by QOLCE questionnaire (Li et al., 2008).

Our participants reported a very slightly lower QOLCE total score than the participants with idiopathic epilepsy from the study of Sabaz, Lawson, et al. (2003) and a partially better HRQOL total score than the children in the study from India (Aggarwal et al., 2011). A possible explanation is that cultural and socioeconomical discrepancies plus cross-cultural differences in HRQOL may include inequalities in healthcare systems, attitudes about treatment (such as hospitalization rates, utilization of emergency care, presence at specialist and private clinics, qualification with antiepileptic medication, use of alternative therapies), and socioeconomical variables (Yam et al., 2008).

In our study, girls reported poorer HRQOL compared with boys. Our finding agrees with other published studies (Devinsky et al., 1999; Räty, Wild Larsson, & Söderfeldt, 2003) in which adolescent girls were at increased risk for developing psychosocial difficulties and lower HRQOL compared with boys. The finding, however, does not support the work of Taylor et al. (2011) in which there were no differences in parent-reported HRQOL between boys and girls. They recruited patients who were newly diagnosed. In another study, gender was not significantly related to HRQOL (Sherman et al., 2008).

In agreement with our findings, some investigators have found that long-term disease results in decline in the HRQOL in children with epilepsy (Ronen et al., 2010; Wu et al., 2010), whereas other researchers have found no difference between epilepsy duration and their HRQOL (Connolly et al., 2006; Miller et al., 2003; Mrabet, Mrabet, Zouari, & Ghachem, 2004; Yong et al., 2006). Childhood-onset epilepsy has a prolonged detrimental effect on HRQOL, not only for children and adolescents, even in adults who are without seizures and free of drugs for many years (Mathiak et al., 2010).

Intervention programs based on psychological support and care are beneficial for both children with long-term epilepsy and their families. Active participation of family members in educational workshops has been shown to improve self-efficacy skills when managing epilepsy. Mutual support groups for both the patient and the family foster improvement of self-management skills and provide valuable information and support (Katz, 2003; Munn-Giddings & McVicar, 2007; Spangenberg & Lalkhen, 2006). Educational programs for children and their families have been shown to decrease the unfavorable effects of epilepsy (Hirfanoglu et al., 2009).

Regarding the fact that duration of epilepsy was an important factor, longitudinal studies to evaluate HRQOL of children with epilepsy over time are warranted. However, in contrast to some previous reports, Szaflarski et al. (2006) depicted that the shorter disease duration was associated with lower HRQOL. This may reflect habituation and adjustment to physical and psychosocial outcomes of disease that might lead to promotions in HRQOL over time (Szaflarski et al., 2006; Taylor et al., 2011). These various findings may be because of methodological differences such as sampling methods, sample size, study design, instruments,

statistical analysis, and data reporting. Thus, it is difficult to compare our findings with other studies.

In our study, children with family history of epilepsy had lower parent-rated specific HRQOL. A family history of epilepsy seems to raise the risk of developing epilepsy by two to three times (Hauser, Annegers, & Rocca, 1996). Family history of epilepsy can increase psychosocial distress. The subjects with a family history of epilepsy are more likely to be distressed if they had inadequate adaptation sources or social support, feel especially susceptible to epilepsy themselves, or have lost a family member because of epilepsy. Similarly, in another study, HRQOL scores inversely associated with family history of epilepsy. Hence, in regression analysis, there was no significant correlation (Sinha, Sanyal, Mallik, Sengupta, & Dasgupta, 2011), whereas results of another study indicated no significant correlation between HRQOL and family history of epilepsy (de Souza Maia Filho et al., 2007).

Limitations

This study had several limitations. The questionnaires were parent reported, and assessments may not exactly describe the children's viewpoints. We did not evaluate the psychological factors related to parents such as anxiety and depression as well as parental knowledge about epilepsy. Because of limited research on HRQOL of Iranian children with epilepsy, a further qualification is the limitation of the findings to Iranian children; hence, we had to compare our results with other countries' study findings. In this study, we had no healthy control group, and HRQOL scores of children with epilepsy were compared with published norms.

Conclusions and Implications for Nursing Practice

Findings of this study are related to nursing and other healthcare fields because educational aspects may result in favorable outcomes. Epilepsy is a medical and personal condition, as well as a social and public health issue, which requires multidisciplinary intervention. HRQOL in children with epilepsy can be impacted by educational and social programs that promote self-management and greater social awareness among patients and the public. Nurses are in a unique position to decease the stigma experienced by many patients with epilepsy in Iran by providing education to parents, caregivers, and the public. Increased attention to the seizure-associated psychological status affecting HRQOL should be incorporated into culturally sensitive care of the child with epilepsy.

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